American Journal of Medical Genetics 64:378–381 (1996)

Experiences and Attitudes Concerning Genetic Testing and Insurance in a Colorado Population: A Survey of Families Diagnosed With Fragile X Syndrome

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This study examined the relationship between diagnosis, experience with insurance underwriting, and perceptions of difficulties with insurance in genetically tested families. Discrimination was strictly defined as the misuse of genetic information in underwriting. Forty-eight families received a survey and thirty-nine (81%) responded.

No insurance cancellations were reported although many families believed that it happened often. The fear evidenced by the respondents was out of proportion to the experiences and 66% of the families reported moderate to extreme worry over losing health insurance.

Genetic counselors and others involved in caretaking of diagnosed families must expand their roles to assist in providing access to local resources and information concerning insurance issues and other social issues. Addressing medical issues alone will not provide the assistance these families require.

KEY WORDS: genetic discrimination, genetic counseling, health insurance, fragile X syndrome, underwriting

INTRODUCTION

Genetic research prompted by the Human Genome Project is producing data which society must attempt to assimilate quickly [Engel, 1993; Durfy, 1993]. An anecdotal body of information proposes that genetic testing can restrict access to insurance [NIH/DOE, 1993].

The potential misuse of information produced by testing is an important ethical component of all genetic research [Billings et al., 1992]. Fear of testing because of the social implications may cause the affected families to refuse the information and assistance that testing would bring.

Insurance underwriting brings conflict between this new medical information and general social interests [Kass, 1992]. One component of the assessment of risk by companies is that all knowledge must be made available for a decision concerning risk to be made. A few studies [McEwen et al., 1992, 1993] have attempted to address the issue of the misuse of genetic information but have been inconclusive.

The goal of this study was to examine the experiences of a group of families diagnosed with fragile X and to compare those experiences with the families' beliefs. Discrimination is strictly defined for the study. How insurance companies act upon applications from families with the disorder compared to what the families perceive as happening was the focus of this work.

METHOD

A self-administered questionnaire was developed to evaluate the attitudes and experiences with insurance purchases in a group of families with fragile X syndrome. A cover letter to the family assured anonymity and promised follow-up with study results.

The list of families was obtained from the Child Development Unit at The Children's Hospital in Denver. The fragile X testing must have been done at least two years before in order to allow time for discrimination to have occurred. All of the families were Colorado residents in order to assure that no other state insurance regulations affected any underwriting process. The child with fragile X syndrome was to be currently living in the home in order to verify that an "insurable interest" existed and that the child would be included in any family underwriting. The total population identified meeting these and other criteria was 48 families.

The questionnaires were prepared and mailed. The families returned them, after completion, by mail. A response rate of 81% (n = 39) was achieved.

Received for publication December 18, 1995; revision received February 5, 1996.

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The questionnaire had four sections. Demographic information collected in the first section verified the inclusion criteria. The second section of the questionnaire evaluated the experiences of the families. The third section allowed expression of any experiences the family wished to relate. Fifteen families (38.5% of responding families) completed this section. The last portion of the questionnaire examined the family attitudes toward insurance and testing.

RESULTS

Demographics of Responding Families

Five of the households did not fully complete the demographic section. A total of 46 children with fragile X syndrome lived in 34 of the responding families' homes (Table I). Twenty-seven of these homes (79.4%) had no children free of fragile X syndrome. Eighty-seven percent of the families were comprised only of individuals genetically related to the affected child. One family reported no carrier mother.

Approximately 36% of the families had only one working adult, and two families reported no working adults; 77% of the responding families were offered health insurance through their employer; 84.6% (n = 33) of the responding families were covered by health insurance at the time the questionnaire was completed; and 81.8% (n = 27) paid a portion (or all) of their family health insurance premium.

Fifty-nine percent (n = 23) of the families had purchased some insurance since the genetic testing. Of these, 56.5% (n =13) had completed a health questionnaire. Thirteen families reported a government sponsored program (Medicare or Medicaid) for at least one member of the family (including the affected child). Three families "did not want to have insurance" and one family "could not afford health insurance."

Experiences With Insurance Underwriting and Renewal Processes

No carriers of the fragile X gene or normal (or unscreened) individuals within the families reported being "rated" (asked to pay more) for any coverage purchased (Table II). Six families reported carriers being declined for coverage, but further examination revealed that all six were part of family applications that included the affected child. Unaffected family members were also a part of these applications and were also declined.

Three families reported that contract riders had been placed on individual and family policies indicating that fragile X related expenses would not be covered by the policy. Most importantly no family reported having any insurance cancelled as the result of genetic testing.

Attitudes of the Families Concerning Testing and Insurance

Six families (15.4%) reported that some family members had refused to be tested because of worry about losing insurance; 43.6% of the responding families believed that it would be more difficult for their families to obtain insurance they need because of the testing; and 30.8% (n = 12) of the families were afraid to change jobs out of fear of losing health insurance.

The families were presented with a Likert scale to use in reporting worry over insurance issues. Approximately 66% of the responding families indicated "moderately severe" to "extreme" worry over these issues. 23.7% reported "extreme" worry.

DISCUSSION

For the purposes of this study genetic discrimination was defined as the misuse of genetic information in insurance underwriting. It included cancellation of the

TABLE I. Study Participants: Demographics of Colorado Families Diagnosed With Fragile X Syndrome

Measure	Proportion of respondents in each category	
	n (families) responding to question	n (% of respondents) in category
Households with no *unaffected* children	34	27 (79.4)
All adults in household genetically related to fragile X (hereafter "fra X") child (assures all included in underwriting)	39	33 (84.6)
Head of household educational level: Those with some college or college grads (greater access/understanding of information)	39	31 (79.5)
Employment: professional and management or skilled trade (probable greater access to group insurance)	39	28 (71.8)
Households with two working adults not fra X affected (probable greater opportunity for access to group health insurance)	39	18 (46.2)
Working for employers with more than 50 employees (greater opportunity for guaranteed issue health insurance with no pre-existing clauses)	39	29 (74.4)
Family offered group health insurance through employer (group insurance less likely to contain permanent riders)	39	30 (76.9)
Families with health insurance now	37	33 (89.2)
Families reporting government sponsored coverage for an affected child (Medicare or Medicaid)	37	13 (56.5)

TABLE II. Reported Experiences With Insurance Underwriting and Renewal Processes

Measure	Proportion of respondents in each category: n responding to question	n (% of respondents) in category
Any carrier or unaffected "rated" (asked to pay more) by insurance company because of fra X in family	39	0 (2 = "don't know")
Family units (including affected children) declined for coverage for fra X	39	6 (15.4)
Fragile X testing was covered by insurance	39	21 (53.8)
Affected children who have been refused coverage for life or health insurance since the testing	39	27 (69.2)
Genetic testing required for any insurance application for any family member	38	0
Riders excluding fra X expenses placed on policies including carriers or unaffected	39	3 (7.7)
Any life or health policy cancelled after the family's testing	39	0
Insurance companies excluding fra X expenses as "pre-existing conditions" (It is unknown whether these riders are for a specified period of time or permanent)	39	13 (33.3)

insurance for a child with fragile X syndrome only after genetic testing. It also included refusal to insure carriers of the trait who can never be affected. The definition of genetic discrimination did not include refusal to cover entire families which included the affected child.

Two examples of genetic discrimination as defined were found. One example was the issuance of riders eliminating coverage for fragile X expenses for unaffected or carrier individuals. At best these riders indicate a misunderstanding of the consequences of the fragile X syndrome. At worst the insurance underwriter was consciously refusing to risk loss associated with the possible birth of an affected child.

The families themselves reported self-defined discrimination based on a misunderstanding of the rules of insurance. In the case of family applications which included both affected children and carrier mothers, it is difficult to know why the insurance company refused the application. Not one company offered to insure the family while excluding the affected child, which leads these investigators to suspect that the carrier status was just as important a factor in the decision as the child's condition.

Cancellation of existing policies was not reported. Many of the families believed this loss to be a great problem, yet no evidence exists that any insurer took steps to cancel policies. One third of the families reported members who either refused to be tested or were afraid of losing insurance but allowed testing to continue (Table III).

The experiences reported by these families belies their fear of discrimination. Although for some families access to health insurance seems to be a problem, most of the families have protection through employer plans.

This small study uncovered no great evidence of true genetic discrimination by insurance underwriters. Sev-

TABLE III. Family Attitudes Toward Genetic Testing and Insurance Availability

Measure	Proportion of respondents in each category: n responding to question	n (% of respondents) in response category
A family member has refused testing because of worries over losing insurance	39	6 (15.4)
Worried, very worried, or extremely worried about keeping health insurance since testing	38	25 (65.8)
Family will not tell or try not to tell insurance agents about testing	33	6 (18.2)
Families have heard about others who have lost coverage after testing	37	17 (45.9)
Those responding yes who believe this to be true	17	16 (94.1)
Families believe that having genetic testing makes it harder to find insurance they need	31	17 (54.8)
Family members report fear of changing jobs because of health insurance worries	33	12 (36.4)
Families which are unaware of the Colorado state sponsored Uninsurable Health Insurance Plan (CUHIP) which provides guaranteed issue health insurance for those unable to find it elsewhere	37	31 (83.8)

eral family applications produced contracts with restrictive riders, but it was difficult to know the genesis of the restriction.

The assessment of the open-ended portion of the questionnaire relies on a qualitative analysis of the written comments of the families. The nature of "beliefs and attitudes," too intricate to be thoroughly examined in a quantitative manner, lend themselves well to this method. The analysis presented here is designed to augment the findings of the balance of the study.

Fifteen of the thirty-nine responding families (38.5%) took the time to write narrative comments concerning their experiences and their concerns. These comments presented a similar focus:

"We're afraid to apply for insurance."

"I worry a lot about finding an insurance company that will take us."

"I worry about getting cancelled."

There is a sense that financial catastrophe is just around the corner. This is evidenced in the high percentage (65.8%) of families reporting moderate to extreme worry over health insurance. Other comments were aimed at the confusion the families encountered when attempting to sort through insurance choices and to understand insurance.

CONCLUSION

An important finding of this study is that a general lack of understanding of insurance and how it works exists among families with even the highest educational levels. It may be that this lack of understanding itself has produced the belief that insurance companies are engaging in discriminatory practices.

In order to provide peace of mind to families, the participants in a genetic study should be offered information on the possible social consequences of the testing. Resources for the solution of any problems should be offered along with information concerning state regulations and underwriting principles. Connections to support organizations and social agencies should be a part of the information.

The role of the genetic counselor is the obvious one to be expanded to assist diagnosed families with the social implications of the genetic disorder. The counselor can prevent misinformation and provide a point of contact for referrals to community resources. Helping the family understand consequences and options as well as medical implications will only become more important as insurance companies and other institutions begin to use the genetic information we are creating.

ACKNOWLEDGMENTS

The authors gratefully acknowledge the assistance of the Colorado families diagnosed with the fragile X mutation. Their concern and their willingness to participate in an evaluation of family matters has made this study possible. Dr. Randi Hagerman's work is supported in part by grant no. MH45916 from the National Institutes of Mental Health and in part by grant #MCJ-089413 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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